

1 AN ACT in relation to aging.

2 Be it enacted by the People of the State of Illinois,
3 represented in the General Assembly:

4 Section 1. Short title. This Act may be cited as the
5 Family Caregiver Act.

6 Section 5. Legislative findings. The General Assembly
7 recognizes the following:

8 (1) Family caregivers, serving without
9 compensation, have been the mainstay of the long-term
10 care system in this country. Care provided by these
11 informal caregivers is the most crucial factor in
12 avoiding or postponing institutionalization of the
13 State's residents.

14 (2) Among non-institutionalized persons needing
15 assistance with personal care needs, two-thirds depend
16 solely on family and friends for assistance. Another 25%
17 supplement family care with services from paid providers.
18 Only a little more than 5% rely exclusively on paid
19 services.

20 (3) Family caregivers are frequently under
21 substantial physical, psychological, and financial
22 stress. Unrelieved by support services available to the
23 caregiver, this stress may lead to premature or
24 unnecessary institutionalization of the care recipient or
25 deterioration in the health condition and family
26 circumstances of the caregiver.

27 (4) Two out of 3 family caregivers, due to being
28 employed outside the home, experience additional stress.
29 Two-thirds of working caregivers report conflicts between
30 work and caregiving, requiring them to rearrange their
31 work schedules, work fewer than normal hours, or take an

1 unpaid leave of absence. For this population, caregiver
 2 support services have the added benefit of allowing
 3 family caregivers to remain active members of our State's
 4 workforce.

5 Section 10. Legislative intent. It is the intent of the
 6 General Assembly to establish a multi-faceted family
 7 caregiver support program to assist unpaid family caregivers,
 8 who are informal providers of in-home and community care to
 9 frail individuals or children.

10 Services provided under this program shall do the
 11 following:

12 (1) Provide information, relief, and support to
 13 family and other unpaid caregivers of frail individuals.

14 (2) Encourage family members to provide care for
 15 their family members who are frail individuals.

16 (3) Provide temporary substitute support services
 17 or living arrangements to allow a period of relief or
 18 rest for caregivers.

19 (4) Be provided in the least restrictive setting
 20 available consistent with the individually assessed needs
 21 of the frail individual.

22 (5) Include services appropriate to the needs of
 23 family members caring for the frail individual, including
 24 a frail individual with dementia.

25 (6) Provide family caregivers with services that
 26 enable them to make informed decisions about current and
 27 future care plans, solve day-to-day caregiving problems,
 28 learn essential care giving skills, and locate services
 29 that may strengthen their capacity to provide care.

30 Section 15. Definitions. In this Act:

31 "Child" or "children" means an individual or individuals
 32 18 years of age or under.

1 "Department" means the Department on Aging.

2 "Eligible participant" means a family caregiver or a
3 grandparent or older individual who is a relative caregiver.

4 "Family caregiver" means an adult family member, or
5 another individual, who is an informal provider of in-home
6 and community care to a frail individual.

7 "Family caregiver support services" includes, but is not
8 limited to, the following:

9 (1) Information to caregivers about available
10 services.

11 (2) Assistance to caregivers in gaining access to
12 the services.

13 (3) Individual counseling, organization of support
14 groups, and caregiver training for caregivers to assist
15 the caregivers in making decisions and solving problems
16 relating to their caregiving roles.

17 (4) Respite care provided to a frail individual
18 that will enable caregivers to be temporarily relieved
19 from their caregiving responsibilities.

20 (5) Supplemental services, on a limited basis, to
21 complement the care provided by the caregivers.

22 (6) Other services as identified by the Department
23 and defined by rule.

24 "Frail individual" means an older individual who is
25 determined to be functionally impaired because the individual
26 (i) is unable to perform from at least 2 activities of daily
27 living without substantial human assistance, including verbal
28 reminding, physical cueing, or supervision or (ii) due to a
29 cognitive or other mental impairment, requires substantial
30 supervision because the individual behaves in a manner that
31 poses a serious health or safety hazard to the individual or
32 to another individual.

33 "Grandparent or older individual who is a relative
34 caregiver" means a grandparent or step-grandparent of a

1 child, or a relative of a child by blood or marriage, who is
2 60 years of age or older and who:

- 3 (1) lives with the child;
- 4 (2) is the caregiver for the child because the
5 child's biological or adoptive parents are unable or
6 unwilling to serve as the primary caregiver for the
7 child; and
- 8 (3) has a legal relationship to the child, such as
9 legal custody or guardianship, or is raising the child
10 informally.

11 "Informal provider" means an individual who is not
12 compensated for the care he or she provides.

13 "Older individual" means an individual who is 60 years of
14 age or older.

15 "Respite care" means substitute supports or living
16 arrangements provided on an intermittent, occasional basis.
17 The term includes, but is not limited to, in-home respite
18 care, adult day care, child care, and institutional care. The
19 term also includes respite care as defined in Section 2 of
20 the Respite Program Act to the extent that such services are
21 allowable and participants are eligible under the National
22 Family Caregiver Support Program.

23 Section 20. Powers and duties of the Department. The
24 Department shall administer this Act and shall adopt rules
25 and standards the Department deems necessary for that
26 purpose. At a minimum, those rules and standards shall
27 address the following:

- 28 (1) Standards and mechanisms designed to ensure the
29 quality of services provided with assistance made
30 available under this Act.
- 31 (2) Data collection and record maintenance.

32 The Department shall administer this Act in coordination
33 with Section 4.02 and related provisions of the Illinois Act

1 on the Aging.

2 Section 25. Provision of services. The Department shall
3 contract with area agencies on aging and other appropriate
4 agencies to conduct family caregiver support services to the
5 extent of available State and federal funding. Services
6 provided under this Act must be provided according to the
7 requirements of federal law and rules.

8 Section 35. Health care practitioners and facilities not
9 impaired. Nothing in this Act shall impair the practice of
10 any licensed health care practitioner or licensed health care
11 facility.

12 Section 40. Entitlement not created; funding; waivers.

13 (a) Nothing in this Act creates or provides any
14 individual with an entitlement to services or benefits. It is
15 the General Assembly's intent that services under this Act
16 shall be made available only to the extent of the
17 availability and level of appropriations made by the General
18 Assembly.

19 (b) The Director may seek and obtain State and federal
20 funds that may be available to finance services under this
21 Act, and may also seek and obtain other non-State resources
22 for which the State may be eligible.

23 (c) The Department may seek appropriate waivers of
24 federal requirements from the U.S. Department of Health and
25 Human Services.

26 Section 90. The Respite Program Act is amended by
27 changing Sections 1.5, 2, 3, 4, 5, 6, 8, 11, and 12 as
28 follows:

29 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

1 Sec. 1.5. Purpose. It is hereby found and determined by
 2 the General Assembly that respite care provides relief and
 3 support to the primary care-giver of a frail ~~or--abused~~ or
 4 functionally disabled ~~or--cognitively-impaired-elder~~ adult and
 5 provides ~~by--providing~~ a break for the caregiver from the
 6 continuous responsibilities of care-giving. Without this
 7 support, the primary care-giver's ability to continue in his
 8 or her role would be jeopardized; thereby increasing the risk
 9 of institutionalization of the frail ~~or---abused~~ or
 10 functionally disabled ~~or--cognitively-impaired-elder~~ adult.

11 By providing ~~improving-and-expanding-the-in-home~~ respite
 12 care ~~services--currently--available~~ through intermittent
 13 planned or emergency relief to the care-giver during the
 14 regular week-day, evening, and weekend hours, both the
 15 special physical and psychological needs of the primary
 16 care-giver and the frail ~~or--abused~~ or functionally disabled,
 17 ~~or--cognitively-impaired-elder~~ adult, who is the recipient of
 18 continuous care, shall be met reducing or preventing the need
 19 for institutionalization.

20 Furthermore, the primary care-giver providing continuous
 21 care is frequently under substantial financial stress.
 22 Respite care and other supportive services sustain and
 23 preserve the primary care-giver and family caregiving unit.
 24 It is the intent of the General Assembly that this amendatory
 25 Act ~~of--1992~~ ensure that Illinois primary care-givers of frail
 26 ~~or--abused~~ or functionally disabled ~~or--cognitively--impaired~~
 27 ~~elder~~ adults have access to affordable, appropriate in-home
 28 respite care services.

29 (Source: P.A. 87-974.)

30 (320 ILCS 10/2) (from Ch. 23, par. 6202)

31 Sec. 2. Definitions. As used in this Act:

32 (1) "Respite care" means the provision of intermittent
 33 and temporary substitute care or supervision of frail ~~or~~

1 abused or functionally disabled or cognitively-impaired-elder
2 adults on behalf of and in the absence of the primary
3 care-giver, for the purpose of providing relief from the
4 stress or responsibilities concomitant with providing
5 constant care, so as to enable the care-giver to continue the
6 provision of care in the home. Respite care should be
7 available to sustain the primary care-giver throughout the
8 period of care-giving, which can vary from several months to
9 a number of years. Respite care can be provided in the home,
10 in a community--based day care setting during the day,
11 overnight, in a substitute residential setting such as a
12 long-term care facility required to be licensed under the
13 Nursing Home Care Act or the Assisted Living and Shared
14 Housing Act, or for more extended periods of time on a
15 temporary basis.

16 (1.5) "In-home respite care" means care provided by an
17 appropriately trained paid worker providing short-term
18 intermittent care, supervision, or companionship to the frail
19 or disabled adult in the home while relieving the care-giver,
20 by permitting a short-term break from the care-giver's
21 care-giving role. This support may contribute to the delay,
22 reduction, and prevention of institutionalization by enabling
23 the care-giver to continue in his or her care-giving role.
24 In-home respite care should be flexible and available in a
25 manner that is responsive to the needs of the care-giver.
26 This may consist of evening respite care services that are
27 available from 6:00 p.m. to 8:00 a.m. Monday through Friday
28 and weekend respite care services from 6:00 p.m. Friday to
29 8:00 a.m. Monday.

30 (2) "Care-giver" shall mean the family member or other
31 natural person who normally provides the daily care or
32 supervision of a frail,--abused or disabled elderly adult.
33 Such care-giver may, but need not, reside in the same
34 household as the frail or disabled adult.

1 (3) (Blank). "Provider" shall mean any entity enumerated
2 in paragraph (1) of this Section which is the supplier of
3 services providing respite.

4 (4) (Blank). "Sponsor" shall mean the provider, public
5 agency or community group approved by the Director which
6 establishes a contractual relationship with the Department
7 for the purposes of providing services to persons under this
8 Act, and which is responsible for the recruitment of
9 providers, the coordination and arrangement of provider
10 services in a manner which meets client needs, the general
11 supervision of the local program, and the submission of such
12 information or reports as may be required by the Director.

13 (5) (Blank). "Director" shall mean the Director on
14 Aging.

15 (6) "Department" shall mean the Department on Aging.

16 (7) (Blank). "Abused" shall have the same meaning
17 ascribed to it in Section 103 of the Illinois Domestic
18 Violence Act of 1986.

19 (8) "Frail or disabled adult" shall mean any person
20 suffering from Alzheimer's disease and who is 60 55 years of
21 age or older and or any adult 60 years of age or older, who
22 either (i) suffers from Alzheimer's disease or a related
23 disorder or (ii) is unable to attend to his or her daily
24 needs without the assistance or regular supervision of a
25 care-giver due to mental or physical impairment and who is
26 otherwise eligible for services on the basis of his or her
27 level of impairment.

28 (9) "Emergency respite care" means the immediate
29 placement of a trained, in-home respite care worker in the
30 home during an emergency or unplanned event, or during a
31 temporary placement outside the home, to substitute for the
32 primary care-giver. Emergency respite care may be provided
33 in-the-home on one or more occasions unless an extension is
34 deemed necessary by the case coordination unit. When there

1 is an urgent need for emergency respite care, procedures to
2 accommodate this need must be determined. An emergency is:

3 (a) An unplanned event that results in the
4 immediate and unavoidable absence of the primary
5 care-giver from the home in an excess of 4 hours at a
6 time when no other qualified care-giver is available.

7 (b) An unplanned situation that prevents the
8 primary care-giver from providing the care required by a
9 frail or abused-or-functionally disabled or--cognitively
10 impaired adult living at home.

11 (c) An unplanned event that threatens the health
12 and safety of the frail or disabled adult.

13 (d) An unplanned event that threatens the health
14 and safety of the primary care-giver thereby placing the
15 frail or abused-or-functionally disabled or--cognitively
16 impaired-elder adult in danger.

17 (10) (Blank). "Primary--care-giver"--means--the-spouse,
18 relative,-or-friend,-18-years-of-age-or-older,-who--provides
19 the--daily--in-home-care-and-supervision-of-a-frail-or-abused
20 or-functionally-disabled-or-cognitively-impaired-elder-adult.
21 A-primary-care-giver-may,-but-does-not-need-to,-reside-in-the
22 same--household--as--the--frail--or--abused--or--functionally
23 disabled-or-cognitively-impaired-adult.-A-primary--care-giver
24 requires--intermittent-relief-from-their-caregiving-duties-to
25 continue-to-function-as-the-primary-care-giver-

26 (Source: P.A. 91-357, eff. 7-29-99; revised 2-23-00.)

27 (320 ILCS 10/3) (from Ch. 23, par. 6203)

28 Sec. 3. Respite Program. The Director is hereby
29 authorized to administer a program of establish-respite
30 projects-for-the-purposes-of-providing-care-and assistance to
31 persons in need and to deter the institutionalization of
32 frail or disabled or--functionally-disabled-or-cognitively
33 impaired adults.

1 (Source: P.A. 87-974.)

2 (320 ILCS 10/4) (from Ch. 23, par. 6204)

3 Sec. 4. No Limit to Care. Nothing contained in this Act
4 shall be construed so as to limit, modify or otherwise affect
5 the provisions, for long-term in-home services being provided
6 under of Section 4.02 of the Illinois Act on the Aging.

7 (Source: P.A. 87-974.)

8 (320 ILCS 10/5) (from Ch. 23, par. 6205)

9 Sec. 5. Eligibility. The Department may establish
10 eligibility standards for respite services taking into
11 consideration the unique economic and social needs of the
12 population for whom they are to be provided. The population
13 identified for the purposes of this Act includes persons
14 suffering from Alzheimer's disease or a related disorder and
15 persons who are 60 55 years of age or older, ~~or persons age~~
16 ~~60 and older~~ with an identified service need. Priority shall
17 be given in all cases to frail, ~~abused~~ or functionally
18 disabled ~~or cognitively impaired~~ adults.

19 (Source: P.A. 87-974.)

20 (320 ILCS 10/6) (from Ch. 23, par. 6206)

21 Sec. 6. Responsibilities. ~~The following requirements~~
22 ~~shall apply for any projects authorized under Section 3 of~~
23 ~~this Act:~~

24 (a) The Department Director shall administer this Act
25 and shall adopt rules and standards the Department deems
26 necessary for that purpose ~~establish target areas needing~~
27 ~~respite care services.~~

28 (b) The Department Director shall make grants to or
29 contract with Area Agencies on Aging and other appropriate
30 community-based organizations to provide respite care under
31 this Act ~~publicize the existence of, and make available,~~

1 application-forms-for-sponsors-seeking-to-establish-a-respite
2 program.

3 (c) (Blank). The--application--forms--shall-require-the
4 following-information-and-any-other-information-the--Director
5 deems-necessary.

6 (1)--Identity-and-qualifications-of-a-sponsor.

7 (2)--Identity-and-qualifications-of-a-provider-and-a
8 plan-for-the-coordination-of-services.

9 (3)--An--assessment--of--the-community-need,-support
10 and-participation-for-respite-services.---The--assessment
11 shall-include-documentation.

12 (4)--Plans--for--the-coordination-and-arrangement-of
13 provider-services-in-a-manner-that-meets-client-needs.

14 (5)--A-fiscal-plan,-including--specific--provisions
15 for-the-utilization-of-existing-reimbursement-and-funding
16 sources-and-the-development-of-local-financial-support.

17 (6)--Plans---for--publicizing--the--purpose--of--the
18 project-and-the-services-to-be-provided.

19 (7)--Certification-of-licensure-or-certification--of
20 any--individual,-agency--or--family--providing-a-service
21 subject-to-licensure,-or-certification-under-State-law.

22 (d) (Blank). The-Director-shall-review-and-evaluate-each
23 application-and--present--each--application--for--review--and
24 evaluation--by-the-Council-on-Aging-established-under-Section
25 7-of-the-Illinois-Act-on-the--Aging.---The--Council--and--the
26 Department-shall-approve-a-number-of-applications-and,-within
27 the--amounts--appropriated,-award-grants-for-the-operation-of
28 respite-programs.

29 (e) (Blank). The-application-approved-by--the--Director
30 and--the--Council--on--Aging-shall-be-the-service-plan-of-the
31 provider.---The-Director-shall-ensure-that-each--service--plan
32 is--coordinated--with-the-designated-area-agency-provided-for
33 in-Sections-3.07-and-3.08-of-the-Illinois-Act-on--the--Aging,-
34 the--local--public--health-authority,-and-any-other-public-or

1 private-service-provider-to-ensure-that-every-effort-will--be
2 made---to---utilize--existing--funding--sources--and--service
3 providers-and-to-avoid-unnecessary-duplication-of-services.

4 (f) Nothing in this Act shall be construed to limit,
5 modify, or otherwise affect the provision of long-term
6 in-home services under Section 4.02 of the Illinois Act on
7 the Aging.

8 (Source: P.A. 87-974.)

9 (320 ILCS 10/8) (from Ch. 23, par. 6208)

10 Sec. 8. Funding. Services Respite--prejects authorized
11 under this Act shall be funded only to the extent of
12 available appropriations for such purposes. The Director may
13 shall seek and obtain State and federal funds that may be
14 available to finance respite care grants--awarded under
15 Section--6--of this Act, and may shall also seek and obtain
16 other non-state resources for which the State may be
17 eligible. ~~Implementation-of-projects-under-this-Act-shall-be~~
18 ~~contingent---upon---the--availability--of--federal--financial~~
19 ~~participation.--To-the-extent-necessary-for-implementation-of~~
20 ~~this-Act,~~ The Department may shall seek appropriate waivers
21 of federal requirements from the U.S. Department of Health
22 and Human Services.

23 (Source: P.A. 87-974.)

24 (320 ILCS 10/11) (from Ch. 23, par. 6211)

25 Sec. 11. Respite Care Worker Training.

26 (a) A respite care worker shall be an appropriately
27 trained individual whose duty it is to provide in-home
28 supervision and assistance to a frail ~~er---~~abused or
29 functionally disabled ~~er--cognitively-impaired-elder~~ adult in
30 order to allow the ~~primary~~ care-giver a break from his or her
31 continuous care-giving responsibilities.

32 (b) The Director may prescribe minimum training

1 guidelines standards for respite care workers to ensure that
 2 the special needs of persons receiving services under this
 3 Act and their primary caregivers will be met. The Director
 4 may designate Alzheimer's disease associations and community
 5 agencies to conduct such training. Nothing in this Act
 6 should be construed to exempt any individual providing a
 7 service subject to licensure or certification under State law
 8 from these requirements.

9 (Source: P.A. 87-974.)

10 (320 ILCS 10/12) (from Ch. 23, par. 6212)

11 Sec. 12. Annual Report. The Director shall submit a
 12 report each year to the Governor and the General Assembly
 13 detailing the progress of the respite care services provided
 14 ~~programs-established~~ under this Act. ~~The--report--shall~~
 15 ~~include:~~

16 ~~(a)--a-financial-report-for-each-program;~~

17 ~~(b)--a-qualitative-and-quantitative-profile-of-sponsors,~~
 18 ~~providers,-care-givers-and-recipients--participating--in--the~~
 19 ~~program;~~

20 ~~(c)--a-comparative-assessment-of-the-costs-and~~
 21 ~~effectiveness-of-each-service-or-combination-of-services~~
 22 ~~provided;~~

23 ~~(d)--an-assessment-of-the-nature-and-extent-of-the-demand~~
 24 ~~for-services;-and~~

25 ~~(e)--an-evaluation-of-the-success-of-programs-receiving~~
 26 ~~grants-for-services.~~

27 (Source: P.A. 87-974.)

28 (320 ILCS 10/7 rep.)

29 (320 ILCS 10/9 rep.)

30 (320 ILCS 10/10 rep.)

31 Section 91. The Respite Program Act is amended by
 32 repealing Sections 7, 9, and 10.

1 Section 99. Effective date. This Act takes effect upon
2 becoming law.